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The Dynamics of Autistic-Academic Partnerships

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The Dynamics of Autistic-Academic Community Partnerships

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Introduction

• Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)
  – Started 2006 by Christina (health services researcher, parent) & Dora (autistic, systems scientist)
  – Uses a CBPR/PAR approach

• Current research
  – Healthcare Study 1
  – Partnering with People with Developmental Disabilities to Address Violence
  – Internet, Community, and Well-Being Study
Systems and Feedback

- Systems are Dora’s favorite thing
- Systems science gives some tools to help understand the dynamics between scientists, majority society, and minorities
- System – a collection of parts related to each other relative to an environment
Properties of Complex Systems

- Long time spans
- Feedback
- Synergy, non-linearity, emergence
- Decentralization
- Generative structures
Minorities and Research

- Minorities have experienced
  - Direct harm
  - Stigmatization
  - Underrepresentation

- Researchers have experienced
  - Difficulty getting study participants
  - Inappropriate study design
  - Failed interventions
Vicious Cycles

- Reinforcing feedback makes change difficult
Participatory Approaches to Research

- Change the relationship between minority communities and researchers
- “Subjects” become part of the research team
- Equitable exchange of power and expertise
- For example, CBPR or PAR
- Research approach, not research method
The Principles of CBPR

• Acknowledges community as a unit of identity
• Builds on strengths and resources in the community
• Facilitates a collaborative, equitable partnership in all phases of research
• Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners
• Facilitates co-learning and capacity building among all partners.
Principles of CBPR, ctd.

• Involves systems development using a cyclical and iterative process
• Focuses on community relevance and on ecological perspectives that attend to the multiple determinants of health and wellbeing
• Disseminates results to all partners and involves them in the wider dissemination of results.
• Involves a long-term process and commitment to sustainability
Community and Identity

- Community is a **unit of identity**
- A "readily available, mutually supportive network of relationships on which one [can] depend."
- Includes shared values, symbols, history, and a sense of emotional safety and personal identification
Communities Defined by Disability

• CBPR typically done with communities defined by race, ethnicity, or geography
• Communities can also be defined by disability, or other traits
• Communities of autistic adults exist
• CBPR is being successfully conducted with communities defined by disability
Traditional Autism Research Dynamics

• “The daydreaming study...”
  – fMRI study about mental “resting states”
  – Autistics “failed” to go into them under the same conditions as non-autistic controls
  – Headlined in the press as autistics don’t “daydream”
“The Daydreaming Study”

• Community response
  – Huh? But, we do daydream!
  – Questions about methods
  – Concerns about stereotyping
Possible Issues with Lack of Inclusion

• How might lack of autistic involvement lead to
  – Issues with study design
  – Inaccurate conclusions
  – Stigmatization in publications
  – Reinforcement of stereotypes in mainstream society
  – Sabotaging of community priorities
Community Priorities

• CBPR focuses on **community relevance**...
• Community priorities can reach researchers though advocacy to majority society
  – But what if self-advocates are excluded from policy?
  – Or dismissed as not able to advocate or even self-advocate?
• Community Priorities can reach researchers directly through participatory research
Participatory Dynamics

**Scientists**
- values, priorities, research funding, cultural context
- treatments/interventions, scientific findings, academic expertise, academic resources, capacitation, credibility

**Majority Society**

**Minority Community**
- advocacy
- values, policy, public perception, services funding, research funding

**Participatory Dynamics**
CBPR with AASPIRE

**Community**

**KEEPS RESEARCH ETHICALLY SOUND AND SOCIALLY RELEVANT**
- Meets Community Priorities
- Ensures Accessible Instruments
- Publicizes Findings
- Has Community Relevance
- Ensures Safe & Effective Recruitment
- Helps Community

**DEVELOPMENT**
- + Focus of Inquiry / Problem Definition
- + Study Design
- + Funding
- Has Scientific Value
- Meets Funder Priorities

**IMPLEMENTATION**
- + Recruit Participants
- + Collect Data
- + Analyze Data
- Ensures Safe & Scientifically Appropriate Recruitment
- Ensures Scientific Rigor

**DISSEMINATION**
- + Draw conclusions
- + Design interventions
- + Translate findings
- Builds on Theory
- Publishes Findings

**KEEPS RESEARCH SCIENTIFICALLY SOUND AND ACADEMICALLY RELEVANT**

**Researchers**

**CBPR Process**
Research Development

- Topic selection
  - Community importance
  - Researcher expertise
- Funding procurement
Research Implementation

- Measurement adaptation
  - Construct selection
  - Wording
  - Instructions and comments
- Interview formats
- Recruitment
- Community and academic partners work together to interpret results

Ensures Safe & Effective Recruitment
Ensures Accessible Instruments
Ensures Scientific Rigor

IMPLEMENTATION

- Recruit Participants
- Collect Data
- Analyze Data
Research Dissemination

- Data and credibility to support policy change
- Web Tools project
- Conferences and workshops like this one

DISSEMINATION

- Publicizes Findings
- Helps Community
- + Draw conclusions
- + Design interventions
- + Translate findings

Builds on Theory
Publishes Findings
CBPR and Systems Change
Thank You

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